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TITLE: Policies as Bridges: Community-Oriented Implementation of HIV Reporting by Name

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ISSUE: HIV reporting by name is a controversial and polarizing issue. In 1997, after 4 years of unsuccessful experimentation with a non-named HIV surveillance system, the Texas Department of Health (TDH) recommended that HIV reporting by name be adopted. To minimize the chance of alienating the affected communities and deterring HIV testing, TDH sought to maximize the role of the communities in development and implementation of this policy.

PROJECT: TDH initially sought community opinion on HIV reporting by name through informal town meetings held throughout the state in early 1998. When it became apparent that no suitable alternative to reporting by name existed, TDH created the Community Consultation on HIV Reporting in May 1998 to advise TDH on the creation of an implementation plan for HIV reporting by name. This statewide group consists of HIV prevention workers, persons living with HIV, HIV clinical/social service providers, members of HIV services and prevention planning groups, infection control and laboratory personnel, and public health workers involved in STD services and HIV/STD surveillance. The charge of this group, which continues to meet, is to provide guidance to TDH on how HIV reporting by name could be implemented with a minimum disruption to their communities. The members of the consultation also bring the concerns and reactions of their communities to the table.

RESULTS: The communities' major concerns (confidentiality of the reporting data, deterrence to testing, and continued access to anonymous testing) were resolved in the first few months of the committee's work, as the members became more familiar with surveillance/public health procedures and purposes, and both public health workers and the communities created shared understanding of each other's priorities and concerns. The group had a significant impact on the contents of the proposal for named reporting, which was adopted in November 1998. The group was instrumental in developing highly effective materials and communication strategies for educating providers of HIV testing about the surveillance system changes. A packet of these materials was widely distributed in advance of the announcement of the newly adopted policy. The members of the group act to promote discussion of HIV reporting issues within their communities, and continue to work with TDH on HIV reporting issues.

LESSONS LEARNED: The primary lesson, that public policy is best created with the full participation of the public, is often ignored. While many members of the Consultation do not agree that HIV reporting by name was the best choice for their community, bringing this diverse group of individuals together in an open and neutral setting to discuss and resolve difficult and controversial issues resulted in an effective and coordinated change which better addressed the concerns of public health, PLWH/As, and at-risk populations.

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